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Spirituality

NOLA MILLIN,
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SHIRLEY McNAUGHTON



Nola Millin

From Nola Millin

It feels good to be back in the "driver's seat" again. I haven't had the opportunity to write the editorial for an issue of **Communicating Together** since March 1996. I have shared the responsibilities of this issue with Tracy Shepherd, a good friend. It has been my pleasure working with her. And I'm not saying that just because she has been my speech pathologist! In fact, she has just *abandoned* me and has accepted a job in London.

The theme of this **Communicating Together** is *Spirituality*. When we first sat down to decide what we would ask people about their spirituality, we came up with the following questions:

- *How do you define spirituality in your life?*
- *Do you practise an organized religion? If so discuss this.*
- *How has your religion and spirituality helped in dealing with your disability? Day to day? Over the years?*
- *How has it helped your family?*

- *Have you ever changed your religion? If so why?;*
- *How do you define God or Higher Power in your life?;*
- *Have you ever struggled with the notion of the existence of a Higher Power?*
- *How important is this Higher Power in your everyday life?*

We knew that spirituality is a very personal and individualized aspect for each person so we weren't sure what kind of response we would get.

When we sent out our letters, it made me ponder over my own spirituality. I was raised in a "Christian" home. We never went to church but my mom told me about the basic principles of Christianity. Christmas is when we celebrate Jesus' birthday, Good Friday is when we remember His crucifixion, and Easter is when we celebrate the fact that He arose from the dead. I didn't think too much about these Christian principles. They were just a way of life. God was there but I wasn't really concerned about Him.

It wasn't until my mom's death that I started thinking about God. I remember after the car accident that took my mom's life, my best friend had come to be with me at the hospital. We were walking by a crucifix and she said she was mad at Him, meaning God. I thought about it and discovered I wasn't really angry at God. I just felt nothing. After my mom's funeral, my uncle stayed with us for a few days. During that time he told me about making Jesus the Lord over my life. It took me eight months before I did it. Hey, I'm slow!

After I became a "born again" Christian, I started attending church. My first experience with a church turned out to be a bad one. The church was very legalistic. There were many beliefs about what a Christian was and wasn't supposed to do. Fortunately, in 1981, I changed churches and started attending a Presbyterian church where I still attend today. St. Andrew's Presbyterian Church of Puce, Ontario is a Bible believing church. Our motto is "A church with a heart to follow after God's heart." Our church is very open to the Spirit of God. I have found the true meaning to Christianity since attending St. Andrew's. So for me, spirituality has had a positive affect in my life. I obviously believe in the existence of God and know He has ultimate control. My belief in God has given me the strength to go on living during the hard times. I couldn't have made it this far in my life without my faith in Jesus and in His Word. In my mind spirituality means believing in something. For me, this something is the Lord Jesus Christ.

It has been interesting to read the articles that we have received. As expected, each has an unique view on spirituality. I'm very pleased to have gotten articles from a few different religions. Many of the articles tend to look at spirituality from a Christian perspective and I would like to apologize for the Christian slant that this issue takes. We certainly realize that spirituality is not limited to any one kind of religion.

I'm thrilled that Lynda Jacko has shared some excerpts from her

upcoming book in the feature article. I have known Lynda for years. We live in the same building. She is an inspiration to many of us. Even though Lynda's speech isn't understandable, she is quite vocal! When Lynda is in the kitchen area, I can usually hear her all the way down the hall. She is either laughing or teasing one of the staff by giving them a "hard time." I'm so pleased that her book is being published because she has so much to share. As you will read, her faith in God has gotten her through many things. I just wish she would start on a sequel.

You will note that the *Perspective* section in this issue is quite large. That's due to the fact that we received a fair number of articles. I was elated to receive three articles from consumers in India. All three of the writers talk about how their faith has helped them. Raja Sen shares at length his beliefs. It is obvious that he feels that his beliefs have helped him in his life. The other two individuals from India, Putul Biswas and Somenath Banerjee, didn't go into as much detail as Raja did but it is apparent they too have a strong faith in God. It is always a pleasure for me to learn about other religions so I really enjoyed hearing about their faith.

Besides the articles from India, Normand Pellerin writes about the spirituality in the special community, Foyer Partage. Partage is a community of disabled people and their helpers who live and work together. It's interesting to hear how such a diverse group of individuals share their spirituality. When reading the article, it is clear that they recognize that the hand of God has been with them from the beginning until now. I was glad to read about spirituality in a community.

In his search for religious meaning, Alan Sunisloe provides another *Perspective* on spirituality. Alan's spiritual walk is in some ways similar to mine. Alan talks about how it wasn't until he was older that he found his faith in God. Alan's church is important to him. I can certainly relate to that. My church means a lot to me since I don't have any family near to me. Like Alan, I have people from my church who help me. It's nice to hear about someone like Alan who has had a positive experience with his spirituality.

As usual, Paul has written an elegant article, this time about his spirituality. I have known Paul for a few years and I have to say that he has incredible faith in God. Paul doesn't push his faith on people. Instead he demonstrates it. I must admit I had to persuade Paul into sharing some of his personal beliefs. I'm glad I did because the part about how the hand of God saved him is wonderful. I'm glad he shared it. In Paul's article, like all the others, it's amazing to see what God means to people and what their spirituality does for them.

From Tracy Shepherd

As I have read through the articles coming in for this issue I have found myself becoming increasingly introspective. Each of our writers comes from a very different background and thus represents different religious and spiritual beliefs. Still, there are certainly many missing viewpoints from this issue. Judy Wine from Israel, for example, would have loved to contribute. Unfortunately, the call for articles came during the busy Passover season.

Keep in mind while reading this issue that the topic can be fairly

heavy. So take your time and enjoy each article. Read the articles more than once. I think I have read the articles each a half dozen times so far and I get a little something more each time. Overall, the notable thing I feel when reading through the issue is that each and every person who has written has a wonderful relationship with the God of their understanding, their Higher Power. I personally envy this since it is an area in my own life that is lacking.

A striking omission from this issue are any negative thoughts and feelings about God and religion and spirituality. Even though we asked many of our contributors if they had ever struggled with the existence of a Higher Power, they said they had not. Wow! That is amazing — to be so close to your own faith that there is no question. I would have thought that people would be calling the notion of a benevolent Higher Power into question every day particularly in families with disabilities and profound sorrows. Maybe people are just uncomfortable talking about it. I mean, when a father of young family is killed in a car crash caused by a drunk driver, doesn't that family ask, "Where was God?" and "Why did He let our father go?" When a woman in her prime of life is struck by breast cancer causing a slow and painful death, "Why?". When a baby is born with serious congenital health concerns, what are the parents thinking and where are they turning for strength? Some clearly are turning to their Higher Power with the notion that with every tragedy God is teaching or showing us something to make us stronger. But maybe sometimes the pain is too strong. Maybe we get mad at God because we simply cannot understand. I think this must happen in some cases. Touchy subject!

In *Teaching and Learning*, George Pigache gives us some excellent ideas on how to start teaching spirituality through meditation. His comment that he is looking for a Spirituality which does not teach answers to questions but helps people to answer their own questions, really hits home with me. I thank him for his thought provoking words. In *Perspectives*, a Muslim family shares insights about their way of life, Islam and its benefits for their family and their severely challenged son. Shamima and Fareed show how they gain strength from their commitment to love, compassion and mercy. Aleks Poposki joins us again in the *Perspective*, this time to discuss his religion and how it has given himself and his family faith that his future holds great things. His father, being a priest in the Macedonian Orthodox church, has clearly provided him with the gift of a very strong faith. Thanks for writing Aleks.

In *As Communication Changes*, Alda begins by expressing how her role as Associate Editor for **Communicating Together** has enriched her life. It has allowed her to get close to and communicate with individuals with acquired communication difficulties on a very personal and emotional level. It is wonderful to see the joy Alda gets from taking the time to help people communicate. In this issue, Steven Hanlon discusses dying and how his spirituality helps him through the acceptance of the idea of death. It is emotional to hear him say that he has done everything in his life that he has wanted to do.

Audrey McGee, in her first contribution to **Communicating Together**, talks to Alda about her life and her stroke and the tremendous difficulty it has caused in communicating. She has taken up painting since her stroke and is greatly enjoying it. As a devout Catholic her faith leads her through

the days in the chronic care hospital where she now resides.

Also in *As Communication Changes* we are lucky to have a sensitive article from Liz Grinberg whose mother is suffering from Alzheimer's Disease. Liz's evolving acceptance of her mother's condition and failing communication skills is quite touching. She explains how caring for people with this disease leaves individuals grappling with questions about God and their own humanity. Liz has worked through these questions with God's help. She can now be at peace just to visit with her mother. Thanks for her heartfelt words.

Since spirituality is a personal and controversial topic, I find it fascinating to hear the stories and beliefs of all our contributors. I personally have gained a great deal from them all and I thank them for their candid discussion of such a difficult topic. I only wish I could be as secure in my own spirituality as they have all shown that they are.

From Shirley McNaughton

It has always given me great joy to witness the lives of many AAC users being enriched by their strong sense of spirituality — in its many forms. This issue provides many examples like those I have witnessed over the years.

As I read the article about Foyer Partage, I could feel again the "multi-faceted Spirit living/working" within the community there. I come away from every visit moved by the warmth and caring each resident feels for the others and knowing its source is a strong faith in God.

As I read George Pigache's article, I wished I could have a long talk with him about the wonderful learning I have derived from adults who use AAC. As George strives to

help his students develop their spirituality, I want to say to him, "Watch your students carefully. *Learn from them as they mature!*" Meditation may indeed provide an avenue to spirituality and that route George plans to pursue. His students' own unique life opportunities provide another path. I have often thought about the circumstances that enable persons with severe disabilities to develop a deep spiritual understanding. It may be the extreme life challenges and the severe restrictions those with disabilities must face. It may be the necessity imposed upon them of being forced to dismiss the superficial elements of life and as a result to perceive its essence. It may be the extensive time spent alone, being able to reflect upon and savour the relationships and events that many of us are too busy to notice. It may be the humbleness that comes with knowing one needs the help of others in many areas and cannot manage completely on one's own. Or it may be the very special friends who come into one's life when one cannot follow the mainstream path. Could God be revealed through all these experiences?

While the spiritual nature of humans may be attributed to different sources and described in different words, its essence can be *felt* whenever it is present. We can assist those who lack functional speech to express their innermost thoughts and questions and we can support their learning to read so they can independently access the thoughts and reflections of others and of their faith. Or, as Alda Steprans so sensitively describes, we can just spend time getting to know a person with a speech impairment better. In return, we gain something we may be too busy to discover for ourselves. Their spirituality takes the form of an unwavering faith. And they share it generously!

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My Life Has Been a Gift From God.

LYNDA JACKO



Lynda Jacko with Sister Corinne

Lynda Jacko has spent many years writing the story of her life. She calls it "My Life has been a Gift from God". The title itself explains how it fits into this issue of **Communicating Together**. Spirituality has been a vital part of Lynda's life. Her story is fascinating and compelling. Lynda discusses candidly her childhood and teenage years with her family. She talks about her feelings freely and leaves you truly feeling her joy and pain. She takes us through to her young adulthood and the struggles she had in finding housing and social activities. Since Lynda's book was actually completed many years ago it doesn't bring us up to the present time. Perhaps an epilogue will be added to describe where Lynda is today.

Lynda's book will be published by *Sharing to Learn* in the very near future. In the article that follows, Lynda has carefully chosen some of the highlights from her book. In the following passages, she has specifically focused on her spirituality which has guided her over her fifty

years and will continue to play a large role in Lynda's life.

Sister Corrine has been an advocate for Lynda and has helped her over the years to ensure that her book is seen in print. She has also saved some funds to contribute to the costs of publishing. As you will read in the following synopsis, Sister Corrine has learned a lot from Lynda, as have I.

After reading these excerpts from Lynda's autobiography, we hope you will want to fill in the gaps by purchasing this *Sharing to Learn* publication and reading the rest of the story. We look forward to its publication this fall and will provide details as to how you can get it then.

Tracy Shepherd

I have been asked to write about how I got to know Lynda and what evolved to make it possible for Lynda's story to be published. Lynda attended *Harmony in Action*, a school for persons with handicaps, three days a week. Because she was physically handicapped, she could not do crafts, nor could she participate in sports. Often she found herself just sitting in her wheelchair watching the activities of others. Her advocate, Sister Madeleine Meloche, became aware of this and took action. After interviews with the *Harmony* staff and the *Children's Rehabilitation Center* in Windsor, Ontario, an *Apple II* computer was provided to *Harmony* by the *Rehabilitation Center* for Lynda's use.

Since the staff at *Harmony* was too busy to teach Lynda how to operate the computer, Sister Madeleine asked me to go to *Harmony* three mornings a week and work with Lynda. I had retired as a teacher-librarian the year before with a good pension so I volunteered my time.

In spite of her severe handicap, Lynda learned how to operate her computer within a month. She composed a form Christmas letter which I photocopied and sent to all her relatives and friends.

After Christmas, Sister Madeleine suggested that Lynda show me the story of her life which she had written using an old typewriter. Even though her original manuscript was filled with mistakes and corrections, it was quite interesting. I suggested to Lynda that she type it into the computer. This way she could correct all the mistakes.

This really appealed to her so she started immediately. To make it easier for her I prepared and corrected her text and put it on five by seven scratch pad sheets. Lynda was only able to use the thumb of her right hand. This thumb served her well during several years of slowly but surely typing her story. At last her dream was coming true. This so encouraged her that she sometimes typed at the computer in the afternoon if her arm was not too tired. I would point out any mistakes that Lynda made on the computer but did not do any typing for her.

Working alongside a person with cerebral palsy for six years was a real experience in **patience**. I love Lynda and I admire her spunk. Sister Madeleine and I plan outings for her and her mother. She especially likes outings to the park or nature centers.

Thanks to Tracy Shepherd who arranged for the publication of Lynda's story, her book will soon be a reality. Lynda's dream will have come true and I will be a better person for having shared my life with Lynda.

Sister Corinne Markham

I hope that you will find this article interesting and that it will make you stop and think about how wonderful life really is even with its ups and downs. Please look for my book. It was very worthwhile for me to write even though it was a lot of work and took a lot of time. I am looking forward to seeing my life in print.

Lynda Jacko

I was born in Windsor, Ontario, July 7, 1947 with cerebral palsy. I didn't come out right like I was supposed to. Instead I came out of my mother's womb backwards. My mother realized that there was something wrong with me. The doctor told her that because of brain damage at birth, I would never be normal. Because of cerebral palsy, I would be a vegetable and I wouldn't learn or know anything.

My Love for the Outdoors

Some of the neighbor's kids used to come to the door and ask Mom if I could go outside and play with them.

At that time I was outside all the time. I never wanted to come in. Mom had to drag me in. I'm still that way now.

Learning to Communicate Without Speaking

After I learned how to spell, I used building blocks with numbers and letters on them to spell out what I wanted to say to my mom and others in the family.

My Father's Drinking Problem

I'm sorry to say that I didn't have a very good childhood because my dad had a very bad drinking problem. It's just that I never felt close to my dad when I was growing up. I used to tell him off in my own way. I used to get so mad at him.

Dad's Problem is Hard on Mom

Why did he get like this? He didn't show any love for us. I felt sorry for him and so did Mom. We knew that he didn't mean to get drunk and do the things that he did. Every morning we heard him promise that he would not do that again. Those were his famous last words. Yet he started all over again the same day. That is just the way things were at home.

In the evening every now and then, Mom went for a long, long walk just to get away for a while but she always came back to us. She not only had a responsibility to us but she loved us very much. Every night after she had tucked us into bed, she would either sit on my bed or lay down beside me. Many times she fell asleep right in my room. One thing she always did was to pray with me asking the dear Lord to help Dad stop drinking.

**I mean church is church
and there is only one God.
... Do what you want as
long as you are happy.**

Crying Out in Pain

One day I started to really cry as if something was bothering me. I had no way of making people understand especially being flat on my back. This kept up day and night for a few weeks. Mom knew that there must be something wrong with me because it wasn't like me to carry on like that. One night Mom tried to make me comfortable and to settle me down. Mom stuck her hand inside the cast on my back and felt something wet. Right away she turned me over to see what it was. Here I was lying in a pool of blood. The cast was digging into my back

very badly. The nurses had not bothered turning me over so I wouldn't be on my back all the time. Since I could not talk to tell them, I cried and cried. You can imagine my Mom nearly hit the ceiling. She was very angry and upset.

Hiding My Feelings

I don't know why but throughout my life I had a great desire to be real close to people and become a part of their lives. For a long, long time, for years as a matter of fact, I felt like this but no one knew about it. I would kid, laugh, tease, horse around with everybody without ever showing my true feelings to anybody. I never cried, I kept everything inside of me. I felt so empty and alone as if I was seeking something in my personal life but I wasn't sure what.

My Family

I especially felt bitter about my Dad. For a long time I thought that he hated me for being disabled and in a wheelchair and that hurt me more than anything. For some reason I was sure that he was drinking so much on account of me.

Larry's Death

My brother Larry's death was a big shock for all my family. It took me a long time to get over this very sad episode in my life.

For a long time I dreamt about Larry every night. That was hard because all the next day I thought of the dream I had about him. Then I went through a stage where I went to sleep asking God to take me home to be with Larry because I missed him so much. I really wondered what heaven was like. For a while I thought of putting my pillow over my head and smothering myself but I never did have the guts to do that. I believe the Lord kept me from doing such a stupid thing, thank goodness. This is the honest truth.

It is at this time that my testimony begins and a brand new life begins for me.

These meetings were a great inspiration to me especially some of the hymns they sang. One of them, 'Love Lifted Me,' did something to me. It was as if it spoke to me of God's love.

My Catholic Religion

It was at this point in time that I really had the urge to change my church denomination and become a Pentecostal. This faith was much more meaningful to me than my Catholic faith.

Finally I got up enough courage to type Mom a letter and explain to her that I wanted to change faith because I really enjoy going to the Pentecostal church. The services are so beautiful and I find joy and happiness which gives me great satisfaction. Everyone seems so friendly there.

So I asked Mom if I can go to this church. Mom said to me, "If you have found what you want in that sort of church and faith, by all means go ahead. I mean church is church and there is only one God. That is

how I look at it so it doesn't matter to me. Do what you want as long as you are happy. That is what is important in life, Lynda."

A Born Again Christian

One day in April, the friends who had been taking me to church asked me "Did you ever think of being baptized in water, Linda?" "Yes, I did think of committing myself to the Lord and living for Him", I joyfully replied. This was the life I wanted. In May, Marg and Dick arranged for me to be baptized. My mom went too but my dad did not want to go and that was that.

My head was put under water for only a second. When I came up, I felt that I had been touched by the Lord. I cried for a few seconds as I could feel the Holy Spirit and God's love within me. Right then and there I knew that my life had been changed. *Praise God!* I will never forget that night as long as I live. This was very special to me. This is how I became a born again Christian and got to know the Lord as my personal Saviour. I have been walking with the Lord ever since.

I was twenty-four at the time.

The Lord is within us and He just slowly takes the bad habits from us and creates a new spirit within our souls. He gives each of us a brand new life if we accept and receive the Lord into our hearts and life. He forgives us all our past sins and gives joy and happiness. Prior to knowing the Lord, I had a terrible drinking problem. Neither my mother's objections nor my own guilty feelings had succeeded in getting me to stop. With the Lord's strength, and to please Him, I stopped going to those drinking parties that I had enjoyed in the past.

The Lord was now my joy. I got into the habit of reading my bible every night, spending time alone with the Lord, praying to Him, giving Him praise and thanks. This has become a way of life for me now and it is something I take pleasure doing because I know in my heart that I'm doing something worthwhile. For some reason I don't get around to doing this every day. When I don't, I feel there is something missing in my life. I pray in the morning also for a few minutes after I'm washed, dressed, and I've had breakfast. I thank Him for this new day which He gives me.

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TEACHING AND LEARNING

How to Teach Spirituality

GEORGE PIGACHE

George is a teacher at the Thames Secondary School in London, Ontario. He is responsible for supporting students in their integrated settings, specifically focusing on the transition years between high school and adulthood.

For those of us who can go places, buy things or use a T.V. remote control, living in a world which gives little nourishment to our spirituality is not so bad because it can be replaced by other things. However, if you are severely physically challenged, especially if you have to rely on augmentative equipment to communicate in an impatient world, looking to the outside world to deal with inner human needs may not be an option.

I teach at a high school in London, Ontario where I am responsible for a program mainstreaming ten students with physical challenges ranging from moderate to severe. When we started the program, I knew little about what I was doing and probably know even less now. However, one thing did become apparent to me. I might want the students to be identical in all areas to the other students in the school. By not accepting that there were needs in their lives which would not be ad-

dressed by the regular curriculum, we were missing something. To try to fix this we arranged with staff from our local children's treatment center, Thames Valley Children's Center, to run a weekly group at our school. The students set their own agenda on topics from communicating with caregivers to sexuality. Spirituality has not yet come up as a topic. This does not surprise me. Like most of us, they reflect the prevailing culture.

The importance of developing our spirituality is being put on the back burner. It is being replaced by the belief that we can buy things to make us feel happy and enriched. For example, in advertising they used to just tell us what they did. Now the advertising message is that *more* will make us feel good. I could argue that developing our spiritual nature to help us pursue happiness goes against all the driving forces in our consumer economy, but that is not my concern here.

What is a concern is that we do seem to be relying more as a society on doing, and less on being. The "opiate of the masses" in our world is consumerism. We don't need to develop our spirituality because we can purchase things to make us feel good. It is no wonder then that the issue of "my spiritual side" is no more a concern of these students than of most people. So what's the problem? Well, the problem is that, unlike the rest of us, they cannot distract themselves from their thoughts by being consumers.

Looking back at my ramblings, I realize that I am trying to delay talking about spirituality. This is because I am not sure in my own mind what it is or how to do it. I believe that if one is to spend one's time marginalized because of a physical disability, to be able to develop your spiritual side is an option that everybody should have. But all these words are still begging

the question of what spirituality really is? Is spirituality a means to an end or an end in itself? This is probably a chicken and an egg type of question. To be able to move on, I would suggest it is a means to an end. Through developing our spirituality we have the ability to achieve our inner goal whether it be peace of mind or some other desired state.

This is why spirituality is such an important issue for people who cannot communicate easily with the outside world. They may have to spend a lot of time living within their own head. In addition to this, the present state of technology in augmentative equipment

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really limits the amount of unrehearsed, impromptu communication possible. This often gives limited control over expression of ideas and development of concepts. If spirituality is viewed as an inner process, it becomes a way by which I am able to choose my own goal, be it order or chaos. Learning how to use spirituality thus enables me to be my own navigator and to go wherever I want to go.

Now before I conjure up too much of an image of a wheelchair van cruising into a desert sunset in a haze of peyote, its occupants searching for the meaning of life, let me just review where we are. I believe that, as a society, we are in danger of replacing spirituality with consumerism and being with doing or getting. I buy therefore I am. This is an option for the majority of us, should we choose it. For people

who are at the edge of our society this may be an impossible option. I believe all of us could benefit from learning to pursue life in a more spiritual way. For many of the students I work with, this is the only way.

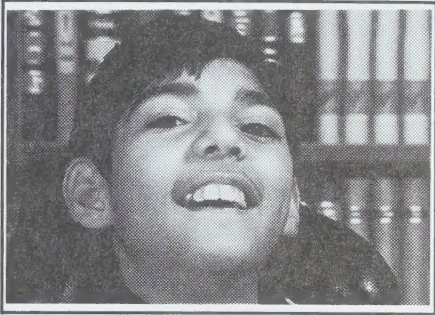
The next step of course is how to do it. I have students who believe in God and who go to church. Their faith seems to give them an acceptance of their situation, and possibly a reason. I am looking for a spirituality which does not teach answers but helps people answer their own questions. Spirituality, as a process, does that. In trying to find a way to help students develop their spirituality, I am turning towards meditation rather than traditional religions.

This is not to preclude the importance of religion in people's lives. As I mentioned above, I am looking for a way to help people focus on their own imagination, hear their own messages, explore their own obstacles and dream their own dreams. I believe that learning how to meditate enables people to do this. Indeed our spirituality may not make us feel good but our feelings will be our own.

This article comes from my belief that however much we may wish students who are physically challenged and use augmentative equipment to be identical to all people, in some areas they are not. Moreover, until our technology becomes much more sophisticated, they cannot be. Yet of course they have the same needs as everyone. By recognizing obstacles we can find ways around them. They may indeed have greater issues to ponder upon and greater questions to resolve about their situation than others. I am sure that there is more than one way to develop our spirituality but I see meditation as a means I would like to try. And now, I just have to do it. §

Denath's Family's Share

FAREED & SHAMIMA DENATH



Yusuf Denath

Fareed and Shamima are proud parents of a young boy, Jusuf, who is severely physically challenged and developmentally delayed. Yusuf developed normally until he was four months of age when he began to have severe seizures. In this article, they share their belief in their religion and their commitment to love, compassion, and mercy.

Spirituality is defined as "attachment to or involvement in religious matters". We are Muslims who follow the religion of Islam (Islam = way of life). We believe in the same God that the Jews and Christians believe in. The Arabic word for God is Allah. Islam presents God, before all other Attributes and names God as the All-Merciful and the All-Compassionate. Concerning the happiness or perfectibility of man: man is not a being composed of only body and intellect. He has also a spirit which requires satisfaction, without which he can never find true happiness. Spiritual satisfaction is possible only through belief in God Almighty and aspiration to 'reach' Him and gain eternal happiness in the other world. In sum, man's real happiness lies in being a servant to God.

We believe in all the Prophets of Judaism and Christianity, but we believe that the Seal of Prophethood was with The Prophet Muhammed, upon him be peace and blessings. All of the Prophets

came with the same doctrine, the fundamentals of which are believing in One God, Prophethood, the Resurrection, Angels, Divine Scriptures and Divine Destiny, and worshipping God. All the Prophets also conveyed the same moral principles. In this sense, all the Divine religions are one and the same. But the flow of history through some epochs varying in cultural, geographical, social and economic conditions required different Prophets to be sent to each nation. Certain differences were to be made in the acts and forms of worship and in the subdivisions of the law, until such time as these conditions allowed the Seal of the Prophets. The Prophet Muhammed, upon him be peace and blessings, could be sent and the religion completed so that, in its essentials, it sufficed to solve all the problems humankind will encounter until the end of time and be applicable in all conditions.

Love, compassion and mercy are the three golden keys to deliverance and peace of mind and heart.

Historically, it is the Divinely revealed religions that have determined what is right and wrong on the authority of their Revealer, namely God, and of the character of the Prophets who conveyed his revelation. We regard Jesus as one of the great Prophets but we do not share the belief of Trinity or that Jesus was the son of God. We believe in his miraculous birth the same way Adam and Eve were created; i.e. by divine intervention. Mercy, love and forgiveness had the first place in Jesus' mission. Therefore, in Islam we give prominence to mercy, love and forgiveness and that the Prophet Muhammed, upon him be peace and blessings, was sent as a mercy for all the worlds, for the whole of existence.

Love, compassion and mercy are the three golden keys to deliverance and

peace of mind and heart. Our son Yusuf's illness brought into perspective the notion that life cannot be taken for granted. It has made us more focused to cope with his needs. At the same time, it has also made us realize that life is valuable. It has made us more aware of other peoples' needs and desires. The one who lacks love and mercy for his own children cannot have those feelings for other people. Love and mercy are among our religious obligations and a means of our spiritual nourishment. If we do not treat children with love and mercy, particularly those who cannot take care of themselves, such as the orphans and physically challenged, their emotional and psychological growth may be stunted and their spiritual life damaged.

Once a man accompanied by a child came to the Prophet. When the man started to kiss and caress the child, the Prophet asked: "Do you feel mercy for the child?" The man said, "Yes". The Prophet said: "Because of your mercy for the child, you also deserve God's mercy, since He is the Most Compassionate of the compassionate".

Mercy means a love that includes feelings of protection and guardianship. Yusuf has been exposed to our religious practices and benefited from our protection and guardianship since birth. The Azaan is a call to prayer that leads to tremendous joy when Yusuf hears it. He also loves to hear the recitation of the Quraan either by us or via the CD or cassette. It has a calming influence on him especially when he is upset or in some type of pain or agony. Overall our way of life (Islam) has had a positive influence on him. His needs and challenges have, in turn, a positive influence on us.

We hope that humanity will regain its commitment to the values of love, compassion and mercy which are and always have been the highest relevance and importance for our well being. §

Two Views of Spirituality and Religion

SOMENATH BANERJEE

I am Somenath Banerjee. I am a 35-year-old man with cerebral palsy. I studied in the Center for Special Education run by the Spastics Society of Eastern India. I live with my parents in Calcutta. My only sister is married and settled in the USA. Five years ago I went to visit her there with my parents. I enjoyed my trip thoroughly. I have lots of friends at the Adult Leisure and Learning Unit of the Spastics Society of Eastern India where I come twice a week for socialization and recreation. I use a wheelchair for going around and communicate through a Bliss board.

How do you define spirituality in your life?

To me, spirituality means faith in God and religion.

Do you practise an organized religion?

Yes I believe in Hinduism. I follow the rituals of Hinduism and go to temples to worship. I also have faith in Christianity and I go to church during Christmas.

How has your religion and spirituality helped in dealing with your disability?

When I feel depressed, I like to go to the temple. Praying to God helps me to regain strength.

How has it helped your family?

My mother spends her whole morning by worshipping God (Puja) and my father takes me to the tem-

ples during the religious festivals. I enjoy the outings and atmosphere of the temple specially Ramkrishna Mission Behlur Math.

Have you ever changed your religion?

No. And I never thought of changing my religion.

How do you define God or Higher Power in your life?

I know there is a God who controls everything.

Have you ever struggled with the notion of the existence of a Higher Power?

No

How important is this Higher Power in your everyday life?

My life starts with morning prayer to God. It is very important in my life.

§

PUTUL BISWAS

My name is Putul Biswas. I am a young woman of 26 with cerebral palsy. I like to make friends and chat with them through my communication board. Some of my friends and familiar people understand my speech. I studied at the Center for Special Education run by the Spastics Society of Eastern India. At present I am a resident of Cheshire Home, a residential care center for young adults with disabilities. I attend the club activities offered by the Adult Leisure and Learning Unit of the Spastics Society of Eastern India once a week. Sometimes I assist senior faculty members to run workshops on using AAC. I have a lot of friends both in India and abroad.

How do you define spirituality in your life?

I believe in God and pray to God everyday.

Do you practise an organized religion?

Yes, I am Christian. I read the Bible and I like Communal service. I go to church during Christmas and on the 1st of January. I pray for a happy and prosperous new year for everyone

How has your religion and spirituality helped in dealing with your disability?

Everyday when I pray I become mentally stronger. This strength of mind helps me to compromise with my disability and gives me the strength to live with my disability.

How has it helped your family?

I cannot say. At present I am living in "Cheshire Home", a residential care center for people with disabilities.

Have you ever changed your religion?

No

How do you define God or Higher Power in your life?

I believe in the existence of a Higher Power. Whenever I get hurt, I take it as a gift from God. During stress, I always pray to God.

Have you ever struggled with the notion of the existence of a Higher Power?

No

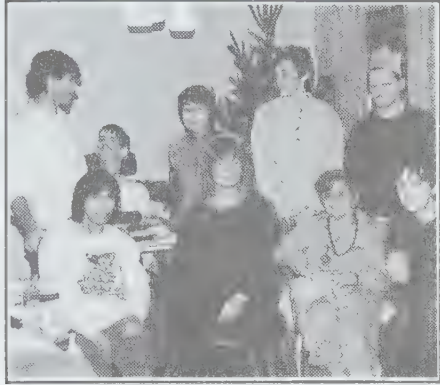
How important is this Higher Power in your everyday life?

I have already mentioned that I strongly believe in the existence of God and this belief has become a part of my life.

§

The Spirituality of Foyer Partage

NORMAND PELLERIN
AND FRIENDS



*Early residents of Foyer Partage
Booth Street, Christmas, 1989*

Normand Pellerin is a Franco-Ontarian born and raised in Sudbury. Normand calls himself a teacher, community worker. He has been at Partage since its very beginning, 15 years ago. He has helped quite a few new Canadian families in Ottawa and is linked with a project in Nicaragua. He travels there most years.

Ottawa Foyer Partage is a community of people who live, work and support three homes. It is a workplace welcoming individuals with multiple disabilities. In this article, Normand and his friends speak mostly of their home on Booth street.

Spirituality or religion is a complex topic. Even before we start our article, we'd like to express a few ideas about God. One must forever appreciate the tremendous freedom of God to be present to any person, any people anywhere in the way, shape or form She/He so chooses! God, the Spirit is the Mysterious One/Other.

We must never be pretentious and claim to know or own God. We must

forever be humble in naming the tiny facets of this Being that we were fortunate enough to have experienced, the few colours of Her/His Rainbowed Personality that have touched us! Often in this world, the image of a God that is distant, powerful, judging us from his/her pedestal is proposed! We, at Foyer Partage suggest with our words and lifestyle a Spirit who is humble, little, grounded and very very close at hand, at heart. She/He (Spirit of God) is simple yet profound and will often find *home* in what She/He has already created, all of us. It is so difficult most times to believe that we are good enough for this Presence, overaware of our limits, failures, disabilities, underaware of His/Her grand desire to be there with us.

On the outside, Foyer Partage, the home on Booth street, appears to be like any other group home in this province, in fact, in the country. If you come closer though, you will soon notice a very big difference, a home with an attitude, a very unique way of life, a way of the heart. You would feel and see a multi-faceted Spirit living/working within us.

Below, a few visual symbols will give you a glimpse of the simplicity yet complexity of the Spirit dancing in our little home: a tree, a beautiful tapestry, our body, creation itself. In the tree, you can see the oneness yet all its parts: the roots, the trunk, the branches, the leaves, fruits and seeds. The seeds at the beginning and at the very end, a cycle of life, seasons of life forever beginning. It talks about fragility and inter-relationship because the tiny seed needs a place, earth to grow. So does the enormous tree! It is the same at

Partage! Now try to visualize a great Sculptor putting bones together, muscles, flesh, then skin. A masterpiece yet so dead. Nothing until the Gift of Life, a breath directly from the Sculptor's lips, lungs, own Soul/Being. We are chosen, every breath, every day for life! The same fragility and grandeur is present in every one of us, in our little Partage community, in the universe, all of creation.

A friend Daniel Mark wrote: "Over years, my experiences in the Partage community have contributed much to my spiritual awareness of and bolstering my faith in God. It is where I first learned my most powerful lessons about forgiveness and compassion; that I was valuable and had worth to offer others in life, and came to understand God loves and welcomes us always."

Even before our home opened, we adopted the philosophy/spirituality of L'Arche. The spirituality of L'Arche announces the dignity and the value of each person. Integrated over the years, this belief has brought into action a very unique Spirit of Welcome. We think it is our strongest gift! We are human, imperfect and we have to pray for, work on and receive this sacred gift every day, with every person.

Like every family, every group, when someone rubs us the wrong way, we grow! Our deepest desire, our deepest aspiration though is to create space for the others — to see them grow to their fullest potential, to believe in themselves and their beauty and dignity. We've seen people healed when they have shared a coffee, a meal, a prayer, or their suffering with us. It is not a healing that magically takes away their human struggle. It is a healing that

takes away the weight, the hurt, the disappointment, the guilt, the marginalisation of that struggle. Our people (Germaine, Justin and Dallacy) have lived hard lives. They have lived with disabilities and have spent numerous years in institutions. This has made them gentle people, wise teachers in letting go and letting God to the rest. Do the best that you can and let go of the rest!

Another person who is well versed in that attitude is our very own Danielle Allen. She is kind of the sap for our family tree touching the roots, the trunk, the branches, the fruits and even reorganizing the earth in the garden if need be, doing so in a gentle, elegant way.

While teaching at Algonquin college in Perth, Danielle met people from the institution in Smiths Falls. She fell in love with these folks who over the years have become her, our people. Danielle, a spiritual woman, was attracted to Jean Vanier (founder of L'Arche), Charles de Foucauld (Little Sisters and Brothers of Jesus) and Mother Theresa. These prophets of our day proclaimed God's will that we value the poor, the little ones. This spirituality invites us to take a second look at people. It calls beloved and rich people who are poor, great people who are littled by life. This Spirit has coloured our outlook since the very beginning. Often, we are still stuck in the first look, beauty of the skin, winning, money, comfort, "I'm better than you!" attitude but we are striving for that second deeper more human look!

People from the institution started telling Danielle about their need for *home*. In our world, in our rich country, many, many people are displaced, looking for a place they can call home. Danielle said "yes!" This yes has followed her and us too, ever since then. Normand once

suggested a name for Danielle: la grande dame (the noble lady). Danielle is very much like a pregnant woman. She trusts God, Her/His fertility, life and the process of life within everyone.

It might be simplistic to say that after the first "Yes!", Danielle let the pregnancy of Partage happen. There was a lot of hard work but she trusted the process. Everything would be O.K. Fifteen years after, she was right - it's still O.K.! We are a fertile people. There is so much life in our midst! She couldn't do it alone! Hyperactive Normand came along. Then the Roman Catholic community of Holy Cross (at first Eleanor, Karen, Barry but quickly most of the parish) dressed with an ecumenical Spirit embraced our foolish project. They adopted us as their own, baptised us Foyer Partage. Then the city of Ottawa built units, some completely accessible for people with disabilities and saved them for us. People, men and women from all walks of life, accepted to sit on our Board and shared their wisdom, time and energy to guide our important decisions.

An unbelievable shower of gifts from committed people affirmed our project, our home. It was like a rock that falls into the water and sends its rippling effects. One yes led to the other. In the end, it was a big resounding "yes" to Foyer Partage.

In 1982 and 1983, it was time for us to move in on Booth street. One by one, we came *home*. Germaine, a French woman (actually Metis) arrived in October 1982. She filled our home with fanfare and much appreciated laughter. Germaine, our elder (she hates being called grandma or old), goes about in her wheelchair. Her gifts are many: Prayer, Acceptance, Welcome,

Then there was Justin, the man of justice, the friend who arrived

shortly after his competency court case. Then there was Dallacy, a simple solid presence, an Inuit woman from Ungava Bay who spent 30 years in institutions before joining us on this common journey home. After a few short months at our home, Dallacy was able to visit her people in Northern Quebec.

Within our home, we have welcomed and celebrated with people of most religions, people from many different cultures and languages, people from many various backgrounds — poor and rich, single and married, old and young, gay and straight, disabled and not yet disabled, atheists and believers, Native, French, English and New Canadians. Our circle has enlarged tremendously in the last 15 years. Actually, our official symbol is people holding hands in a circle. It's quite beautiful!

Who is living and working in this little home on Booth street today? Danielle, Germaine, Justin, Dallacy, Paulette (Nova Scotian, "Mother", organizer), Michaela (a young German woman, artist, free spirited), Paula (administrator, peaceful, good listener), Phanel (Haitian, wise, respectful), Paul (coordinator, creative), Connie (peaceful woman) and Normand (man of justice, generous, energetic). The eleven of us are dressed with six different cultures, seven different languages if we include Bliss and sign language, women and men aged 20 to 69. Diversity!

Often, community life is glorified but it is extremely demanding and can be rather hectic sometimes. Community means living together, sharing (our name in French: Partage) a common lifestyle, work, beliefs and numerous differences. We try to fill each day with respect, flexibility, forgiveness, perseverance —love. Many days, we have to ask

for help from above because most of these nice words are very far from our hearts. Try it!

Most people living and working in our home believe in God. Many participate in the religious celebrations at Holy Cross parish. The people of Holy Cross adopted us at the very beginning and have helped us tremendously. Over the years, we have grown and befriended many of them. Others celebrate in the Anglican or United Church communities. A few believe in Jesus but don't practise and one man is an atheist. A wise person who had studied all religions to find the core values came up with seven words: unity, truth, respect for life, freedom, love, responsibility and fairness (justice).

Though individuals may practise different organized religion, Foyer Partage as a whole is Christian. It has made a profound choice to respect each person's own spiritual journey. Without being overly proud, we have embraced a way of life, a core spirituality that could be summarized by the seven words mentioned above. In the past, we have had Roman Catholic, Anglican,

United Church, Quaker and Native spiritual/religious celebrations in our home. Other times, it has been quiet prayerful reunions with no particular colour other than offering of the people we carry, their needs, the joys sorrows and thankfulness of the day. In our way of life, we choose to give life, empower ourselves and others. Many of our people had some of their powers and rights removed while residing in the institutions. Under the quiet guidance of Paul at the house and Danielle at our workplace called Computer Wise, we aspire to empower our people and ourselves. We aspire to equality and justice, to life-giving education, work, recreation involving such things as silkscreening of cards and t-shirts, computer work, peeling potatoes to feed street people, caring for kids, talking "integration" to schools, participating in house and board meetings and evaluations.

Justin and Normand in their talks to young people in schools invite them to use their hands to receive, to take because we are people with needs to give because we are caretakers, protectors. We are a generous

people. We call it multiplication (making more with less), communion (enlarged community). We have kept in touch and often helped our visitors, neighbours, new Canadians, other people with disabilities. We have helped them move, read, write, compute, translate, defend rights, get an apartment. We have helped people in Haiti and Nicaragua get money, wheelchairs, walkers, dental equipment and more. Abundance! The image that comes to mind is a huge circular dining table with more and more room for people to be fed. On a videocassette film made on Justin and our home, we say: "Canada is a beautiful huge country! Let us try to create as much space as we possibly can in this country, in our school, our home, our heart."

We have tried to create a space, give you a glimpse of our little home, our God. She/He has been faithful to us, present during our celebrations, joys, trips, and our difficult times, back operation, a cancer, our fights, our littleness, our fears! We are forever thankful! The heavens embraced the earth, our home! We are loved! So are you! §

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My Views on Religion

RAJA SEN



Raja Sen

My name is Raja Sen. I was born 29 years ago to a middle class Bengali family. My father is a retired foundry engineer and my mother is a housewife. I have an elder sister who is now married and herself a mother of two children — a son and a daughter. Her in-laws stay quite near to our house.

I joined the Spastics Society of Eastern India when it was less than one year old. I successfully wrote the O'Level Examinations in Arithmetic and Human Biology in 1988. I also did my Class X Examination under the National Open School. Then I successfully finished my computer training from Nehru Children's Museum. Finally in October 1995 I was employed in the computer division of my school.

I like meeting people but my blurred speech often prevents them from becoming friends. When I was studying for my Class X examination, one of my subjects was accountancy. At that point, one of my friends who was a chartered accountant came and taught me the subject. But he has left and gone to Dubai.

I am unable to walk and stand. I travel by taxis and auto-rickshaws. I can even travel to a place which is at a short distance from my house in my wheelchair.

I like reading novels and other story books. William Shakespeare and Thomas Hardy are my favourite authors. I am fond of watching tennis matches and international cricket matches on the television network.

It is generally believed that it is none other than the Almighty who created the universe and the earth. It is He who made the various landforms on earth - lakes, oceans, seas, rivers, and mountains. Man himself believes that it is God who brought him to his native place.

Primitive man had no shelter, no clothes to wear, not sufficient food to keep him healthy. He used to wander around the jungles using stones to light fires and collecting fruits from trees to satisfy his hunger. Gradually, as centuries elapsed, man used his gift of intelligence to create a more comfortable living for himself through the invention of luxury items. Today, thousands of years later, science and technology have enabled man to reach out to far-away lands within a fraction of a second. In spite of these technological advances, man has not changed in his beliefs and spiritualism. He still reposes full faith and confidence in religious practices and faith. For example, a Hindu student will always pray to God before he ventures forward to his examination hall. He strongly believes that if he has complete belief and full faith in God then The Almighty would 'support' and 'guide' him to yield positive

results. This argument is true to some extent. I have seen that, if we pray to God with utmost faith and devotion, in most cases we will be blessed with positive results.

Disabled persons and their families have complete confidence and faith in God. They have often had strong and positive attitude towards Him and religious beliefs. Parents believe that if they seek for his presence and blessings in a whole-hearted manner and with positive determination then he might in return reward them with positive rewards. This notion is true to some extent. In my everyday life activities, I have noticed parents of persons with cerebral palsy engaged in serious, whole-hearted worship of Him. In most cases, they have been 'rewarded' with significant positive outcomes.

When I was born with cerebral palsy, my parents had little hope for me. They were very concerned about me. They were completely in the dark about what to do with me and where to take me for proper education and rehabilitation. Apart from taking me to various doctors, they also sought spiritual support from various hermits and other men of religious belief. They often sought pious help by offering their precious gifts in the form of food, clothes and even expensive jewelry. Initially, there were no positive changes in me. Even so, they did not lose their confidence and belief in Him. They continued to pray to Him with utmost patience. This continued for several years. Surprisingly, in due course, my parents noticed remarkable changes in me. Slowly

but surely I began to achieve several milestones in my life. Initially I could not sit up without any support. Then, to everybody's astonishment, a day arrived when I was able to sit up independently. Gradually my mode of communication improved and I was able to talk with ease with my relatives, neighbours and friends.

When I was six and a half my parents took me to Bangalore, a beautiful city in South India. There I met 'Sai Baba' who was more like a representative of God. He was gifted with magical powers and used to produce 'Bibhuti' by simply waving and turning his palms. My mother began to weep and clearly showed him her anxiety and frustration. He assured her that her son would get suitable rehabilitation in due course. After a few days, we noticed that his prediction came true.

A few months after our return we received information that a special school for the rehabilitation of persons with cerebral palsy had been started.

My mother is a strong believer in God. Despite her busy household work schedule she makes it a daily habit to take time off to worship God by offering sweets and flowers. She also performs annual rituals of worshipping Laxshmi by offering flowers, sweets and foodstuffs. Apart from this, she makes a point of visiting the temple at least once a fortnight seeking His blessings.

One of the most important festivals is the festival of Durga Puja. Mother Durga is a Goddess of Power. She is worshipped for fourteen days when she comes to visit her parental home with her four children. Everybody buys new clothes during the festival of Durga

Puja and it is customary for her to buy one for the Goddess Kali.

Over the past few years my parents noticed dramatic and amazing improvements taking place with me. My communication skills as well as my physical abilities are continuing to improve. God gave me the power of intelligence and it gives me tremendous pleasure to note that I have been able to take advantage of that power. My power of intelligence enabled me to pass my school leaving examination and successfully complete computer training. After several years of sacrifices and effort, I finally got the opportunity to earn money and stand on my own two feet. My friends and relatives always tell me that all my achievements are due to my concerted efforts and sacrifices. But I strongly believe that it was with God's utmost support and faith that I have been able to achieve so much in life. §

My Religion and My Disability

ALEKSANDAR POPOSKI

Aleks first joined us in the March issue to talk about employment. At that time he was beginning a student placement at the Children's Rehabilitation Centre in Windsor, Ontario. This has now led to a summer job for Aleks due to his dedication and hard work. Here he discusses his spirituality.

In my family religion is a big thing. I guess part of it is because my father is the thirteenth priest in a row in our family - that's where our family name "Poposki" comes from: "pop" meaning priest in Macedonian.

Through my religion, Macedonian Orthodoxy, I look at spirit as something that is invisible, something that can't be hurt, or felt, yet the most important thing to the human body, which isn't a part of it. The spirit comes from God when we are born, and returns to God when we die. Through our spirituality we conquer all evil and celebrate the good things in life.

I guess my religion and spirituality has helped me deal with my disability by giving me courage and hope, as well as everybody else —

that I will succeed in life. Right now I feel that my religion and spirituality has given me several strengths, one being my talent in computers. I say this because I feel that I am pretty good at computers and through this talent I'll earn a living, support a family and so on. I look forward to my future: raising a family, having a career, making a living, etc. I think that my religion has also helped my family by giving them hope that I'll be successful in life, and once again start a family.

As I look at one of the questions for this article: "Have you ever struggled with the existence of a Higher Power?" I can comfortably say no. I never have struggled with the existence of God, because of my hope and courage to look forward to my future. §

My Search for Religious Meaning

ALAN SUNISLOE

Alan Sunisloe was raised in Queenston Ontario. He attended the Niagara Peninsula Crippled Children's Centre until he was 21. Shortly after he moved to Participation House in Binbrook. Four years later to an apartment in Hamilton. He is pursuing a bachelor's degree in religious studies at McMaster University. His interests include computers, bicycling, travelling by himself, and Bible studies.

Religion is seen as a set of beliefs about God and often going to a place of worship. It has to do with creeds and dogmatism, as the secular world would have the general public believe. Being religious is often frowned upon especially to the "wise and wonderful" politically correct. I regard this definition as too narrow. I would widen it to include things such as materialism, political ideas, or anything you strongly believe in. I would argue that those who sell their energy and time, almost their soul, to the business world, the sports world, or the general world, are just as religious as a devoted missionary or the common man who loves the Bible and the God therein.

When I see politicians expound their views with such zeal, I conclude they are very religious, especially when their political views are far from the norms of society, for example, the extreme left. The man who spends a major portion on any hobby or a sport may be more religious than a good churchgoer. I

always question why yet the churchgoer is labeled "religious" in a derogatory way while the fanatic of any other thing is not frowned upon.

My first encounter with religion was with the radio ministers in my bedroom radio. My family chose not to follow any religion. My mother's father was a Sunday Lutheran, a good man who picked some worldly habits in his road of life. Dad's family was raised in the Catholic tradition but completely rejected it. In my hour for searching for God, I first read the publications of the Watchtower Society. They seemed to be in accord with the Bible until one scratched the surface. Common sense and scholarly integrity are man-made. Being spiritual is more essential in understanding the Bible. Nevertheless, using logic and plain old common sense is essential in Bible study. Rather than reading their magazines, I started to read the Bible for myself and could not get what this group was saying to coincide with Biblical truth. I found it helpful to consider everything the Bible says about a subject and note its context, before I considered whether a doctrine was biblical or not.

From about 1976 to 1978, people from the Central Gospel Temple in St. Catharines picked me up from our Queenston home and took me to the Sunday morning service. I was really blessed by Rev. Jack Counsel. Unfortunately he left and a minister came from Indiana to replace him. The new minister had the heart to win souls for the kingdom of God and he created much hype. He greatly lacked however in his ability to preach a challenging message for the believer.

When I got to Binbrook Participation House, Barb Laughland, a very dedicated volunteer, took me to her Binbrook Knox Presbyterian Church. It was a fairly good congregation. The minister was an older man that I now classify as a liberal. It

has been thirteen years since I heard him preach, but I never heard much Bible doctrine from his lips.

In 1983, I did what many of my disabled colleagues did and got my own apartment in Hamilton. I started attending Stanley Avenue Baptist Church, where I still attend every week. It is a friendly congregation of about 150. Our official motto is "A caring congregation in the heart of Hamilton for more than a century testifying for Christ and committed to his Word". I like this church because it is a Bible church. It stays near the traditional interpretation of the Bible. Between 1600 and 1800, and some say presently still, there has been a tendency to shift away from relying on the Bible for truth to exulting human thought as the gauge for truth. This is called modernism or liberalism. We totally reject this notion. I feel we need to get to the traditional theology of the church, as taught by Calvin, Luther, the Puritans, among others, not because it is tradition, but because it treats the Scriptures with the respect they deserve.

As to reactions from my fellow churchmen, it has been rather interesting to note the extremes. At one end of the scale there are a few people in my church who see me as a retarded child. I tend to write these off because, as in general society, there is a small percentage of people who do not understand the difference between a physical disability and a mental one, even when they are shown the difference. The rest of the people are very helpful to me. In fact, because my family support network is minimal, the church tends to be my support network when I need help. A few men of the church have always helped me by fixing my bicycle, taking me to the airport and the occasional move.

Overall I give Stanley Avenue Baptist Church an A plus in helping me. Cur-

rently plans are underway for a ramp to get to the sanctuary of the church. Presently a dear friend helps me up the stairs every week. The same friend, Bruce Paterson, drives me to church weekly and has spent many hours over the years fixing things around my apartment. Other people in the church may do one or two specific things over the year, but these people can be counted upon and I appreciate their help very much.

From 1988 to 1992 I was fortunate enough to take a side trip on the road of life and became an actor with the Rolling Thunder Theatre Company in Brantford, Ontario. Sponsored by the Brantford Participation House, this company toured mostly in the province performing skits about disabled people. During this time, I attended Mount Zion Church, a charismatic congregation. It was good, but lacked the disciplined and learned tradition of an old-fashioned Baptist church.

The state of society worries and saddens me. Unlike societies of the past, our society does not really have standards for moral behavior based on the Bible or anything else. I think this is why we are seeing such awful decay of society. Crime, greed, violence, intolerance of ethnic minorities are on the rise. Pollution is often a result of greed. Manufacturers make huge profits and many consumers won't pay more for non-polluting consumer goods. The rich are greedy and often the poor spend the little they have on vices. All this makes me sad. Sexual immorality, as defined biblically, always leads to unhappiness. I am much grieved by the curse of people demanding everything instantly. It seems people are not looking at the possible terrible results of their actions, especially in the area of drug abuse. People of my generation (I am a young 41) are not giving our precious younger people role models.

The Innocently Poor

Another concern of my heart is the state of disabled people, especially the

severely disabled. I am also concerned about what I refer to as the innocently poor of the world. The innocently poor are those who are not poor by their reckless living, but by circumstances beyond their control. I think Canada should give more to the needy of the world. Not doing so is a great sin of Canada. Let's fulfill our agreements with our native countrymen. With such human need, I say shame on people who want the government to spend on luxuries such as cultural institutions and amateur sports. I also say it is a shame that people raise money for such minor things when there are so many more important projects such as feeding the world and helping the unfortunate.

While I will only go to a church that is fundamental, such churches need to do more for the innocent poor. Often I pray that North Americans will be more generous and will centre their givings to the most needy and deserving. Giving a portion of your income to the needy, even a small portion if you are not well off yourself, can really bless you whether you are religious or not.

One thing, among others, that I love about the character of the God of the Bible is his concern for the poor and how that concern is displayed all over His Word. How I thank the Lord that He commanded, yes commanded, his Old and New Testament people to help the needy. All over the Bible, God tells people to help the needy. Moses put it in the Law. Psalms and Proverbs have many verses describing how God blesses those who help the needy. The prophets condemned people for neglecting the poor. Jesus is known as the friend of the outcast. This is great news for people with disabilities. The Gospels record Jesus dealing with many infirm people. Probably some of these people had neurological conditions, such as cerebral palsy. What did Jesus do to them? He never rejected them! He did not instruct his disciples to build 1200 bed institutions to keep them out of society. Jesus

never said disabled people are a burden of society. He loved them! Canada had a great record of helping disabled people, but the record is being tarnished somewhat, especially in Ontario. I wish the churches would preach about this subject a bit more than they do.

Another interesting thought from the Bible is the idea of the smallness of man versus the greatness of God. Scripture portrays God as all knowing, all powerful, and all loving. I marvel at the fact that God even bothers with us. Again, this is great news for people with disabilities. Since able-bodied people are so small to God, a disabled person, 90% of the time insignificant to non-disabled, is almost as big or small to God as a non-disabled person. Since all people are in a way insignificant to God, (insignificant in a sense, but He loves us) the disabled and non-disabled are equal before God. The people with disabilities may not be able to do the physical work or donate large sums of money, but we can please God by praising him mentally, praying for others, perhaps writing about the Gospel, and encouraging others. The fact that persons with disabilities are welcome in the Kingdom of God is great news. There are some words in a language that people love. One of my favourite words is temporary. According to the Bible, disability is temporary. In the Kingdom of God all people will have perfectly functioning bodies. I can't wait. Our earthly lives, even without disability, are nothing compared to the future God has for his children.

The Lord Jesus has kept over me 25 years since I met him in His Word. Studying the Scriptures, praying, giving yourself to the needy, and obeying His Will are important aspects of the Christian life. The Christian life starts with a confession of personal sin, belief in God's forgiveness through the sacrifice of Jesus, and making Jesus as Lord of your Life.

§

Thanks for the Memories

ALDA STEPRANS



Alda Steprans

Having an interest in people and how they think has been important to me for a long time. But really understanding how important and rewarding it is for me to listen to people's stories in a more active way is a more recent discovery. It is a discovery which began when I was studying for my Master's Degree at the Ontario Institute for Studies in Education (OISE).

Peter Lindsay, then my professor, asked his students to spend time with a person who has a disability and find out how that person is empowered. I will always be thankful to him for that experience.

Eighty-five percent of the residents in the chronic care hospital where I work as a nurse, cannot talk.

I thought it would be fascinating to see how these people are empowered. At that time, I did not really believe that they were. For my assignment, I spent a few hours a week with Bill, a resident who had had a stroke a few years before and could not communicate verbally. Bill could say a few words but, for the most part, he repeated words other people said to him. At first I felt very inept, inadequate and uncomfortable sitting with him for long periods. I spent many quiet hours by his side, watching his world, his reactions to it, the reactions of other people to him. The more time I spent with Bill,

These amazing people, who have such great difficulty expressing themselves, have taught me an incredible amount about the human spirit, about hope, about caring and love.

the more I got to know him, the more fascinating his world became and at the end of our "study" I felt that I had been given a wonderful gift. I learned that his life, which had sometimes seemed far less than perfect to me, had many redeeming qualities. I learned that Bill did have some controls over the actions of others, especially to those others who cared to take the time to communicate. He could communicate a lot with his facial expressions. His wife, Vera, was a very empowering person in his life, sometimes solely because of the great respect and love she always has shown for him.

I felt so enlightened, so uplifted about what Bill and Vera had taught me that I wanted to reach out to

others who had difficulty communicating and see what they could teach me. Although I spend time with these people when I nurse them, I usually just don't have the time while on duty, to listen to their stories. During my eight hour shift, there is unfortunately little time to focus on more than meeting the basic needs of all those people I have to care for.

At OISE I had been exposed to this magazine, **Communicating Together**. It showed me that there are many people who have difficulty in communicating, but who have learned how to share their thoughts and feelings in a variety of ways. Their experiences were not so different than those of the people I cared for. So it was that I started to go to the hospital as a volunteer, just to spend time and to really communicate with more of the residents I cared for. I felt that their stories would be of value to many others who read **Communicating Together**, just as the contributions of other **Communicating Together** writers are so helpful to many of my patients.

Listening to, talking to, and truly communicating with such contributors to this magazine as Brian Pamplin, Steven Hanlon, and now Audrey McGee, whom you will meet in this edition, have been the most wonderful gifts. I have been permitted to share in these people's private lives and feelings, their strengths and weaknesses.

Sometimes this listening has required a great deal of energy from all parties concerned. When Brian was sick, it took long hours for him to express his thoughts. I became tired just watching him struggle to communicate what was important to

him. I never ceased to be amazed however at his drive, his ability to share and keep on telling us what was so vital to him. I miss him so very much.

Similarly, communication is exhausting and frustrating for Steven. I come home amazed that he has never lost his temper with me. Some days when we work on an article, I understand little of what he is saying and make him repeat, repeat and repeat. He comes up with the most unique ways of making his thoughts perfectly clear to me. I am amazed at his creativity in finding methods to communicate.

Audrey spends many weepy moments while telling me her story. I see how painful it is for her to remember, to struggle to find the right letters, the right words. Yet, she never gives up and always finds some humour in the situation.

Mrs. Cornish, who contributed an article once before will share some

thoughts again in the next issue. She feels amazed that anyone would be interested in what she has to say. She doesn't feel she has the skill to communicate how special her relationship with her son, Bruce, is. Yet, when she starts to write, the words do come pouring out, and the story that emerges shows her strength and courage as well as Bruce's.

Many of my patients are religious and religion helps them maintain hope and courage. Each person is spiritual in a different way and it is important to find out how each person sees himself in relation to the world around him so that strengths and coping mechanisms can be identified and used during periods of life that are not so rewarding, but also during periods of contentment.

I cannot say that I am a deeply religious person. I have, however, found that spending time listening

and trying to understand these special people, is a very spiritual, and rewarding experience. I thank these people for letting me into their lives, for sharing so many painful and happy experiences with me. Although I still have much to learn about how to listen and communicate with people, these amazing people, who have such great difficulty expressing themselves, have taught me an incredible amount about the human spirit, about hope, about caring and love. I have come a long way and I'll never be able to thank them enough. I would recommend this pleasure, of truly communicating with any person, but especially with a non-verbal person, to anyone who would care for a memorable, meaningful experience. §

Thoughts on Living and Dying

STEVEN HANLON &
ALDA STEPRANS

(Italics are parts added by Alda)



Steven Hanlon

I am not religious, but I believe in God.

Everything about dying scares me. I didn't get to say good-bye to Eric. (*Eric is a neighbouring resident who died a few days before our interview.*) It is important to say good-bye.

I don't feel that I am dying right now. I've had five people close to me die — my mum, my dad, my grandmother, my wife's father and my uncle. It makes me feel lonely. It's hard. I think about dying a lot, because people around me have died. My mother died of cancer. She had a lot of pain and was very skinny. I felt helpless. I am afraid of pain and not being able to eat. It is important to take life one day at a time.

Believing in God helps me when I think about dying. I believe in heaven and hell. I've tried to be good. I think I'll go to heaven. That makes thinking about dying easier.

I've accomplished pretty well everything I've wanted to in life. There isn't anything else I really need to do.

Having come to live in a chronic care hospital has made me realize that I am closer to dying. I do think I'll be well cared for here. The staff like me and will care about me. I like the church services here. The Salvation Army services are fun. God gives me strength.

My belief in God also helps me in the way I live every day. It helps me be more patient and be a better person.

Steven's wife, Kim, came to visit one evening. When I told her that Steven was writing about death and dying, she mentioned that Steven's heaven would certainly be full of lots of chocolate! §

AS COMMUNICATION CHANGES

Meeting Audrey

AUDREY McGEE &
ALDA STEPRANS



Audrey McGee

Hello! My name is Audrey McGee. I am 75 years old. My birthday is on September 12. On March 7, 1996, I had a stroke at home. I woke up in the middle of the night. The covers were all over the place. I couldn't walk. I had to go to the bathroom and I was living by myself. I lowered myself to the floor. I wanted to get to the phone, but I couldn't. I lay on the floor until morning. In the morning, my neighbour came to check on me and found me on the floor, but I didn't know I had had a stroke. I was crying.

My neighbour called an ambulance. The ambulance attendant asked me how old I was. That's when I realized that I couldn't talk. It was very scary! I didn't know what had happened to me.

I was brought to emergency and was admitted to the hospital. I was very sad and depressed. I felt hopeless. The worst thing about the stroke was not being able to talk or spell. My right side was, and still is paralyzed, but that didn't bother me as much as not being able to talk. I couldn't communicate my needs or

feelings. People spoke to me and asked me questions. I couldn't answer.

I think the stroke was related to some knee surgery I had on January 10, 1996. I had the knee surgery to help repair the damage rheumatism had caused. After my stay in hospital I went to a convalescent hospital for three weeks and then went home.

Four years ago my husband died. He had a heart attack. He was a good friend and I miss him very much. Living with the effects of the stroke would be easier if he were alive. I could live at home and he could take care of me. He also would just plain understand what is important to me. I took care of him after his hip surgery. He was a fire fighter.

I have one daughter, Vickie and two grandchildren. Shawn, the older grandson, and his fiancée, Karen, look in on me all of the time. I presently live in a chronic care hospital. My other grandson, Justin, lives in New Orleans.

I cannot walk or talk much any more, but I have learned to paint using my left hand. Painting has helped me learn to use my left hand more. I enjoy painting and a volunteer at the hospital is helping me write a book about my life. I never painted before I had my stroke and started when I came to the chronic care hospital to live, but my mother was an artist. I have some of her paintings at home. I used to knit a lot. Now I do needlepoint when a volunteer helps me. I used to make hats and I still like to wear them.

I can say some words clearly, but it's hard for many people to understand me when I speak. I am going to speech therapy and am improving.

I hate it that I can't spell properly. I used to be a good speller. Sometimes, I don't see well. Right



Audrey's latest painting

after the stroke I couldn't spell at all. That was really frustrating. I still feel frustrated from time to time, but not as often. I keep on learning and will until I die. I can read the newspaper. Sometimes it is hard. The words just don't register. What helped me get through all this ordeal is that I am very religious.

I was raised as a Catholic and I still am a devout one. I went to a school where I was taught by nuns. My patron saint is Saint Jude. I pray to him often.

The priest comes into the hospital where I now live, twice a month, once to say mass and once to give us communion. God helps me. He gives me hope for everything. He gives me strength. I often need that strength. I seldom feel tired and have never needed much sleep. I watch the news on my TV until midnight and still wake up early.

God also gives me lots of patience. One has to be very patient when one can't do things for oneself and always has to wait for help.

God has given me many gifts. I used to read — that was a gift. Now, reading has become hard. The words just don't click sometimes. It's very tiring.

§

Spirituality and the Alzheimer's Patient

LIZ GRINBERG

Liz Grinberg is a nurse. Her mother, Anne Smith, has Alzheimer's disease. Although Liz has cared for many people, caring for her own mother has brought Liz many challenges and insights. She shares some of these in this article.



Anne Smith

Spiritual:

The "life force springing from within us all that pervades our entire beings, and includes the emotional, the ethical, the social, the intellect and the physical dimension."

"It is that which gives meaning, purpose and direction to life. It may be understood in a religious, philosophic and humanistic sense."

Spiritual care:

Care which searches to discover and nurture the inner person and the framework of meaning and values through which it is expressed."

(Flynn, 1980)

When I told people I was attempting to write an article on spirituality and the Alzheimer's patient, their reaction was surprise and often bewilderment. How could a person who can't remember her name or where she is have a spiritual life? How could a life in a nursing home surrounded by the infirm and elderly have meaning or direction? I admit I shared these feelings before my experiences with my mother when she was finally admitted to a nursing home with Alzheimer's disease.

It is a sad fact that our society has little patience for the old and confused. In the media, they are portrayed as wrinkled, white-haired, doddering and unproductive — not whole people to be respected for their wisdom and life experience. It is hard to imagine the shame of the person experiencing the first symptoms of forgetfulness and the gut wrenching realization that these changes will only get worse. Alzheimer's disease is horrible. It slowly robs us of our loved one and often changes them before our very eyes to an angry, belligerent and difficult person we no longer recognize. Communication becomes strained as words are misinterpreted and patients have trouble understanding simple instructions and conversation. Social skills learned through a lifetime also slowly disappear and basic daily needs like dressing and bathing are impossible for the person to do without help. It is painful regression to childhood.

My mother has lived in a nursing home for almost two years. For the first year, her life was a constant turmoil of agitation and insecurity. During that time, my sister or I visited her almost every day. These

times were not fun. We had difficulty accepting the diagnosis and felt guilt and anger that this horrible thing had happened to our mom. We often felt abandoned by friends and family who found visiting too painful.

But as the years have passed, things are better. Our mother has accepted her new home. She recognizes the caregivers and when the family visits, she will say "I am not sure who you are but I know that I love you." We share very simple pleasures — an apple, a walk outside in the garden or sharing a meal in the dining room with the other residents. Rather than always trying to "do" something, we often just sit together and enjoy the moment. As in most other afflicted patients, my mother has a strong need for security and affection. The things that made her happy in the past are still important. She has been an active member of the church and a volunteer for many charity groups. And, I believe, she still has a need for spiritual care.

Weekly church services are given by local clergy. It is interesting to see the different approaches used by the worship leaders. Some use humorous stories to illustrate their lessons. Other try to emphasize the special gifts the residents can offer each other — a smile or a kind word of encouragement. But they all emphasize the same key points: treating each other with dignity and respect despite their many frailties. Often the most forgetful person participates in the worship by reciting fragments of a remembered prayer or hymn. It is quite amazing to see how much of the church ritual lingers in memory. People with dementia are often living in a state of

chaos and confusion experiencing the loss of their independence, home and faith community. Often in a person who had a faith background, the symbols of worship (Communion, prayers, scripture) stay in their memory and can be of great comfort.

Caring for people with Alzheimer's is a challenge. By treating them as real and whole people, we must grapple with questions about our own humanity, about who and where God exists in life. Christian theology teaches us that we are created in God's image and that God's spirit exists in each of us. In traditional native spirituality, God is all around us, particularly in nature. Many people experience God in these common everyday things. Sometimes my feeling of closeness to God occurs when I listen to a great piece of music or when I am alone outside in the garden. I am sure patients with dementia still have these feelings too — their memories and communication may be limited, but ability to feel love and communion with God is not. Our spirituality must be nurtured. It does more than help us cope with life. It empowers us and gives us hope in the face of suffering.

I have found my experience to be one of spiritual growth. At first I did feel overwhelmed and horribly sad over my mother's condition. Slowly I have accepted her disability and daily learn patience and strength by caring for her. I have learned that I don't always have to "do" things for her but just be there as a caring companion. What has helped? I learned as much as possible by reading about dementia. I spoke to my pastor, friends and family of other residents about how they cope. With two friends, we have started a monthly craft class for the residents which has been a success. I also



Anne Smith — celebrating her 76th birthday with her family

found a wonderful book that discusses spirituality in people suffering from dementia that has been a great source of comfort and information.

"The forget-me-not is an appropriate symbol for those afflicted with dementia. These people force us to wonderingly consider how such fragility survives the cold world that is so indifferent to them. They are too delicate and often hidden from our eyes in institutions. But when the caregiver, like the weary climber, kneels before them, they can show us by their presence that we are near to the Holy who lives within them."

(Everett, 1996)

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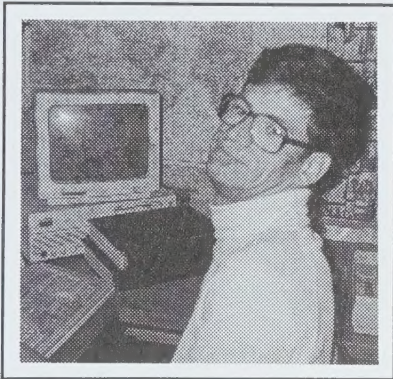
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PAUL'S PLACE

Spirituality: The Calling Within

PAUL MARSHALL



Paul Marshall

Over the past couple of weeks as I thought about putting this column together, I really struggled with what I would say. This topic is very individual and potentially an explosive one to deal with. As I thought about writing an impartial article, I realized that I couldn't write one that would not be from the heart. We all have our own definition of spirituality and live according to these beliefs. Before I go on, I should tell you that I have a very strong belief in the Christian trinity. This article is based on this framework. I realize there are many kinds of religions and many beliefs. With this in mind, I hope this article will not offend you or any of your beliefs.

Spirituality and the supernatural down through the centuries have bothered mankind. If we can't explain it or rule over it then we are at a loss. Spirituality is one thing that we are always trying to explain and put limits on. The world stresses that life is here and now. When we touch on issues like this, it takes us out of the here and now mindset, and throws each one of us into the unclear and unknown. An uneasy feeling comes over us when we hear spiritual words like God, Jesus, the Holy Spirit, pray, death, repent-

ance, forgiveness, judgment, sin, and grace. Our society is shouting loud and clear that there shouldn't be only one God but many gods. Therefore, we don't have any good platform on which to base a belief in one God. It seems if we can't explain a thing — beyond our five senses — it is not worth explaining or believing in it. We like to be in the driver's seat —

Spirituality is a calling that comes from within. We can't define it or put it in a box and say: "Here, I am giving you the gift of spirituality". It is a very individualized thing.

ruling our own "lifestyle". We don't like it when things are beyond our own capabilities. Our senses and our knowledge are becoming gods that we worship, because we can comprehend and rationalize the clear and hard facts. We question if it really matters if there is just one God. We would like God to take more of a "show and tell" role in the world and especially in each of our lives. Could God be already doing this and we just don't see it. I wonder?

We fear what is unknown and don't allow ourselves to view that there is a power and a resource that we can't comprehend. One of the major questions found in the bible is found in Mark chapter 4 verse 41 *"Who is this? Even the wind and the sea obeys Him."*

God is God. If we don't believe in the God of the Bible, it doesn't mean that the facts are untrue. I can't make a believer out of you nor should I try to sway you towards my spiritual beliefs. It is not my job nor

do I have the right or the power to sway you. However, we can't discount that mankind does have a spiritual side to him. If we do discount this, I personally feel that we are missing a huge part of our being. We also know there is a huge growth of the Christian faith and a growing interest in the Bible all over the world.

In my life, the God of the Bible has proven beyond any doubt that He is. Therefore I must live my life in this belief. The Lord has and will be the one who quiets the outer and also the inner storms of my life. My faith in the Lord is the empowerment that drives me. Countless circumstances which I want to have control over are out of my hands. Consider one example that really made the fatherhood of a God real in my life. I was walking to a meeting in Toronto. As I was walking over a bridge, I started to fall toward the road. I did not fall however as I was allowed to wrap my arms around a light stand. It was the only thing that saved me from falling onto the road, where cars were rushing by. The word "lucky" has nothing to do with it. It is all about seeing the guiding hands of my heavenly father. In the Bible, it talks about God having control over everything. We can acknowledge it and live at peace with it or we can try to live with a mindset that we and "mother nature" are ruling.

Spirituality is a calling that comes from within. We can't define it or put it in a box and say: "Here, I am giving you the gift of spirituality". It is a very individualized thing, but it can't help but be a very public thing if we tag it and live a lifestyle according to it. I hope we all can acknowledge that there is a world beyond our eyes. §

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